The HPV Epidemic

A voice for hope
Who we are, what we do and how we do it.
Welcome to one of a series of presentations on the work of Throat Cancer Foundation.

In this presentation we are focussing on the Human Papillomavirus (HPV) Epidemic.
Our mission

The Throat Cancer Foundation is dedicated to the prevention of throat cancers through research, education and vaccination.

We aim to support and give a voice to those whose lives are touched by throat cancer. We raise public awareness of the causes, symptoms and prevention of throat cancers.

We passionately pursue, and lobby for, access to a “Gold Standard” of treatment for all and universal vaccination against the Human Papillomavirus (HPV) strains which cause throat cancers.
We are...

- Founded by a cancer survivor and guided by cancer experts – we exist to lessen the impact of throat cancers and offer support and information to all those affected

- Dedicated to supporting anyone affected by throat cancers

- Supported by leading, world-renown medics and scholars

- UK based with global reach

- Determined to work towards the prevention of throat cancers. If current trends continue unchecked cases of HPV + Oropharyngeal cancer will exceed cases of cervical cancer by 2020
Jamie Rae

Jamie, Founder and CEO of the Throat Cancer Foundation, was diagnosed with Oropharyngeal Cancer in May 2010. A successful entrepreneur and philanthropist he was at that time preparing to sell Redeem PLC, an international socially responsible business he had founded in 1999. Under his leadership, Redeem PLC donated in excess of £10 million to charity. Fortunately, Jamie went on to both survive the cancer and sell the business.

Alarmed and concerned by the lack of information about the causes, treatment and prevention of this disease, Jamie was driven to set up the Throat Cancer Foundation.

Derek Stewart OBE, Chairperson

Derek’s pioneering patient involvement work and personal experience of throat cancer make him the ideal candidate to chair the Throat Cancer Foundation. Born in Scotland, Derek was treated successfully for Cancer of the Larynx in 1995. A former teacher, Derek is a well respected patient advocate at a local, network and national levels.

He founded and became Chair of the Consumer Liaison Group and played an integral role in the development of patient participation in the establishment and work of the National Cancer Research Network and Institute. His contribution to Health Services in particular cancer led to being awarded an OBE in the Queen’s Birthday Honours list 2006.

Currently Derek is the Associate Director for Patient & Public Involvement at the National Institute for Health Research for the Clinical Research Network (NIHR CRN).
What we do…

• We raise awareness around throat cancers and their causes, particularly HPV.
• We support research into the causes of throat cancers, their prevention and cure.
• We raise awareness of Human Papillomavirus (HPV) and the role of HPV in throat and other cancers.
• We are campaigning to introduce a gender neutral, universal vaccination programme for HPV to ensure that everyone is better protected against HPV related cancers.
• We are building a network of survivors, carers and professionals who can offer mutual support and understanding – a sympathetic, peer-led community, both face to face and via an online forum.
• Our comprehensive online resource covers every stage of a cancer diagnosis – from initial symptoms, to side effects of treatment, through to long term recovery. We are a one-stop shop for all people affected by throat cancer – patients, loved ones and professionals.
• We will ensure patients and loved ones are made aware of what we regard as the “Gold Standard” of care. The “Gold Standard” is the best and most effective treatment ensuring the best quality of life outcomes.
How we do it...

Our Clinical and Scientific Advisory Team - a coalition of world-renown experts - verify our content and also support our campaign around HPV. The team are pre-eminent scholars in their fields and are at the forefront of medical advances.

We advocate for patients and their loved ones to ensure they receive the best and most appropriate care for throat cancers. We work with cancer care specialists to advocate best practice and ensure patients know their rights under the NHS constitution.

We work with a range of worldwide agencies to ensure best practice for diagnosis, treatment, care and recovery. We are UK based with global reach.

We support research projects in order to learn more about cancer, HPV and vaccination. We are lobbying Government to change the current vaccination policy.

We use our extensive press and media contacts, as well as our high profile Ambassadors, to continually raise awareness.
Clinical & scientific advisory team

Professor Christopher Nutting
BSc, MBBS, FRCP, FRCR, MD, ECMO

A graduate of the University of London, Professor Christopher Nutting is one of the most eminent Oncologists in the UK, and joins the Throat Cancer Foundation’s advisory team after overseeing the treatment of the charity’s CEO Jamie Rae for throat cancer in 2010.

Lead Clinician of the Head and Neck Unit at The Royal Marsden since 2002, he was appointed National Clinical Lead in Head and Neck Cancer by the Department of Health and the Cancer Services Collaborative in 2003. In 2006, he became Chairman of the National Cancer Research Institute Committee for Head and Neck Cancer Research, and the following year became President of the British Oncological Association.

Professor Hisham Mehanna
Bmed Sc (Hons), MBChB (Hons), FRCS (Glas.), FRCA (ORL-HNS)

Professor Hisham Mehanna graduated from University of Glasgow Medical School and completed his ENT training in Glasgow in 1994. Professor Mehanna then undertook a specialist fellowship in Thyroid and Head & Neck Surgery at the world-renowned Head and Neck Regional Centre in Auckland, New Zealand, before joining the University Hospitals Coventry in 2004, where he is now the Lead Clinician for Head & Neck and Thyroid Cancer.

He is a member of the British Association of Head and Neck Oncologists, Treasurer of the Otorhinolaryngological Research Society and Academic Secretary of Midlands Institute of Otology. He has recently been made an Honorary Professor of Head, Neck and Thyroid Surgery.
Professor Margaret Stanley OBE
BSc, PhD, OBE, FmedSci

Professor Margaret Stanley OBE is Professor of Epithelial Biology in the Department of Pathology at the University of Cambridge.

She has served on several research council committees and was a member of the Biology and Biotechnology Science Research Council from 2000–2003. In 2004, she was awarded the OBE for service to Virology, before being made a Fellow of the Academy of Medical Sciences in 2005.

Her current research focuses on mechanisms of host defence and the development of vaccines and immunotherapies against Human Papillomaviruses (HPV), the cause of cervical cancer as well as a rising cause of throat cancers.

Professor Ian Frazer
AC, FRCPE, FRCPA, FAA, FATSE

Ian Frazer was born in Glasgow and graduated in Medicine from University of Edinburgh in 1974. After completing residency in Edinburgh he emigrated to Australia in 1981.

Dr Frazer is an leading pioneer in HPV research. He is the co creator of the HPV vaccination.

He is the recipient of more than twenty awards in his field, including the Prime Minister’s Prize for Science in 2008 and the 2009 Australian Medical Association Gold Medal. Frazer himself administered the first official HPV vaccination.
Clinical & scientific advisory team

**Professor Simon Rogers**
BDS, MBChB (Hons), FSD, RCS (Eng), FRCS (Eng), FRCS (Max), MD

Professor Simon Rogers has been Consultant Maxillofacial Surgeon at the University Hospital Aintree and Honorary Reader at University of Liverpool since January 1999. Specialising in Oral and Oropharyngeal Cancer and Microvascular Tissue Reconstruction, Professor Rogers is part of a multidisciplinary Head and Neck team.

Professor Rogers now lends his support to the Throat Cancer Foundation with a vested interest in improving health related quality of life (HRQOL) for throat cancer patients, something he feels passionately about.

**Mr Kenneth Mackenzie** MBChB, FRCS(Ed)

Mr Ken Mackenzie is the Consultant Orthinolaryngologist Head and Neck Surgeon, Greater Glasgow & Clyde and Honorary Clinical Senior Lecturer, University of Glasgow.

As one of the UK’s leading Head and Neck Surgeons Mr Mackenzie brings his wealth of experience to the clinical advisory team. Based in Glasgow at the Royal Infirmary and Gartnavel Hospital he graduated from the University of Dundee in 1978 and was appointed to his current position in 1989. Since that time he has developed his sub-speciality clinical and research interests in Laryngology, Complex Upper Airway Disorders and Head and Neck surgery.

He is past President of The Scottish Otolaryngological Society, past President of Section of Laryngology and Rhinology, Royal Society of Medicine and past Chairman of Head and Neck Section, ENT UK. Currently he is Specialist Advisor to the Chief Medical Officer and Chief Scientist for Scotland.
Dr Mary Wells

Dr Mary Wells is a Senior Lecturer in Cancer Nursing at the School of Nursing and Midwifery in Dundee.

Initially moving to Dundee to work as a Macmillan Clinical Nurse Specialist in Radiotherapy and Oncology, Dr Wells was appointed Clinical Research Fellow in Cancer Nursing at NHS Tayside and the University of Dundee. In 2003, she was seconded to set up the new Maggie’s Centre in Dundee, where she was Centre Head for the first year.

Since taking up her role at the School of Nursing and Midwifery, Dr Wells has completed a PhD and has conducted a range of research studies in Supportive Cancer Care. Her current research focuses on head and neck cancer survivorship and rehabilitation.

Lorraine McCreary

Lorraine McCreary is a leading dietitian and nutritionist based in Scotland and founder of Dietscotland, an organisation which helps people with nutrition and to understand attitudes and behaviours towards food and eating.

In addition to her work with Dietscotland, Lorraine has over 17 years experience of working within the NHS across a number of clinical specialties. Lorraine graduated in 1995 from Glasgow Caledonian University and began working at The Southern General Hospital, working there until 2008 as the Senior Cardiac Specialist Dietitian in the Cardiac Team. As well as The Southern General, Lorraine has worked for The Priory and NHS Lanarkshire as well.
What is HPV?

HPV is the Human Papillomavirus, a very contagious virus which lives on the skin and generally accepted to cause almost all of the cases of cervical cancer in women.

This virus has over 100 strains, the majority of which are harmless. There are, however, some strains of HPV which are not and cause serious health problems.

HPV is a leading cause of cancers of the throat, anus, cervix, vulva and penis and genital warts.

Currently a significant proportion of the population are not protected against these life threatening illnesses.

The burden of HPV puts a substantial strain on the NHS, in terms of both cost and resources.

HPV causes life limiting or life altering cancer every single day. Throat Cancer Foundation is campaigning to reduce the impact of HPV related cancers.
Why is HPV such a big problem?

The number of people contracting HPV related cancers continues to increase. We are now faced with an epidemic of HPV positive cancer.

HPV - an ever increasing problem
The HPV-related cancer burden

Cumulative risk per 100,000 cohort born in 2000

Key:
- Males HPV 16/18
- Males Non HPV 16/18
- Females HPV 16/18
- Females Non HPV 16/18
HPV and rising Oropharyngeal Cancer incidence (USA)

Percentage of Oropharyngeal Cancers related to HPV infection*

<table>
<thead>
<tr>
<th>Year</th>
<th>HPV + Cancers</th>
<th>HPV - Cancers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1984 - 1989</td>
<td>16.3%</td>
<td></td>
</tr>
<tr>
<td>2000 - 2004</td>
<td>71.7%</td>
<td></td>
</tr>
</tbody>
</table>

Oropharyngeal Cancers / 100,000 population

<table>
<thead>
<tr>
<th>Year</th>
<th>HPV + Cancers</th>
<th>HPV - Cancers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1988</td>
<td>0.8</td>
<td>2.0</td>
</tr>
<tr>
<td>2004</td>
<td>1.0</td>
<td>2.6</td>
</tr>
</tbody>
</table>

This shows the rise of HPV related Oropharyngeal Cancer over the last twenty years. The increase is significant and if this trend continues we can expect more cases of Oropharyngeal Cancer than Cervical Cancer by 2020.

*Information supplied by Professor Margaret Stanley OBE. University of Cambridge.
Further evidence of the rise in the cases of HPV related cancers of the throat.
**HPV and Oropharyngeal Cancer incidence (UK)**

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of cases of Oropharyngeal Cancer*</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>1060</td>
</tr>
<tr>
<td>2010</td>
<td>1780</td>
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Study from Institute of Head and Neck Studies and Education (INHANSE) Coventry period 2006 – 2010

*Information supplied by Professor H. Mehanna. University of Coventry.*
Increasing incidence of anal cancer (Scotland/England)

Since the 1970s the incidence of anal cancer in Scotland has more than doubled in both sexes.

Incidence rates in England from 1986 to 2003 also nearly doubled in both men and women.

Here we can see the rates of anal cancer increasing over the last 20 years. The burden of anal cancer is particularly felt by men who have sex with men (MSM). The current HPV vaccination policy excludes MSM and fails to protect them from HPV. The Throat Cancer Foundation is campaigning to change this discriminatory and dangerous policy.
HPV 6 & 11 associated diseases*

Laryngeal papillomas
Rare: 4.3/100,000 children
Morbidity: > 4–6 surgical interventions / annum
Costs: £4 million / annum (estimated)

Genital warts
Common: > 8600 new cases (UK, 2009)
Costs: £47.16 million / annum (estimated)

*Information supplied by Professor Margaret Stanley OBE. University of Cambridge.
Near disappearance of genital warts after commencement of national HPV program (AUS)

Here we can see the massive reduction in cases of genital warts since the introduction of HPV vaccination – with the critical exception of MSM. This inequality must be dealt with.

Key:
- Women < 21 yrs
- Men Sex Women < 21 yrs
- Men Sex Men
- Women ≥ 30 yrs

Almost 90% decline in new cases of genital warts in both men and women < 21 years old

Here we can see the massive reduction in cases of genital warts since the introduction of HPV vaccination – with the critical exception of MSM. This inequality must be dealt with.
Preventing HPV related cancers

There is no cure for HPV but there is a vaccine. The vaccine is only given routinely to girls in the UK.

The Throat Cancer Foundation is actively campaigning for universal, gender neutral vaccination. A female only vaccination policy is inadequate, discriminatory and detrimental to public health and must be changed as a matter of urgency.

We support further research into the dangers of HPV and what can be done to protect everyone from HPV.

By acting now we can halt an epidemic of preventable cancer. HPV cancer kills and is always life altering. Vaccination will protect future generations from life threatening cancers.

We have gathered world-wide support from some of the most eminent medical professionals, scholars and researchers – all of whom share our vision to protect all young people from HPV related cancers.
Why Gender Neutral Vaccination?

There are several compelling reasons which we believe support the need for the vaccine to be offered to all young people, not just females.

The current policy relies on herd immunity to protect people from HPV. The current premise is if all girls are vaccinated, then by virtue of herd immunity all boys will also be protected. This is simply not true.

Men who have sex with men (MSM) will not be protected as they fall outside the herd. This leaves them vulnerable to genital warts, anal, penile and head and neck cancers.

There is not an 100% take up of vaccination among females. The gaps in vaccination make the herd immunity policy inadequate and leaves people vulnerable to preventable disease.

Some people have advocated that sexually active men who have sex with men (MSM) be offered the vaccine. This is inadequate as the vaccine is not as effective once someone is sexually active.

Men who have sex with women who have not been vaccinated will also not be protected by the herd immunity approach. In Europe, there are currently no vaccination programmes for girls in Cyprus, Estonia, Finland, Hungary, Lithuania, Malta, Poland and Slovakia. Vaccination rates for girls are also much lower than in the UK in many European and other countries, including the USA.

The cases of HPV related cancers are as we have shown, increasing. Vaccination for all is the most effective way to ensure the future safety of men and women from HPV.

Australia, Canada and the USA have already committed to, or recommend the vaccination of boys and have a clear and progressive approach to HPV vaccination. The UK should emulate their example.
How you can help…..

The Throat Cancer Foundation (TCF) is a registered charity, and as such, your help is vital to us.

Your support and generosity will enable us to reach out to all those touched by throat cancers and enable us to be a Voice for Hope.

Here are some of the ways you can help us:

• A sponsored ANYTHING (e.g. silence, swim, walk, bike ride, abseil, bungee jump, – anything!)
• Organise an event with your friends or colleagues. This could be a coffee morning, lunch, supper, garden party, bow tie to work day, themed event – we love creativity! Fundraising literature can be downloaded from our website
• Take part in a challenge event – donate your challenge to help ours, e.g. London Marathon, Great North Run, Overseas treks or similar. Here at TCF we are all about T.E.A.M. spirit because Together, Everyone Achieves More!
• Participate in our events. You can find details of all our official TCF events on our website www.throatcancerfoundation.org
• Consider making a one-off, regular or legacy donation

No matter how small your contribution, please remember many trickles make a waterfall and every penny will make a difference – Thank you so much.

Please visit our website for further information www.throatcancerfoundation.org
Information for Corporates

Our corporate partners are vitally important to the Throat Cancer Foundation as part of a multi-agency, collaborative approach to our work. There are many ways in which you can help us – including information sharing, sponsorship in kind, sponsorship of our high profile events or other financial support.

We have a powerful, international network of contacts and a world-renowned Clinical and Scientific Advisory Team who are determined to help us affect change – could your organisation be a part of this? We believe we can offer benefits to many corporate partners.

For further information on how we can work together please contact Liz Gregg-Smith or Jamie Rae on 0141 280 1702 or email lizgs@throatcancerfoundation.org
Information for Trusts

Or relationships with trusts are vitally important to the Throat Cancer Foundation as part of a multi-agency, collaborative approach to our work.

We have a powerful, international network of contacts and a world-renowned Clinical and Scientific Advisory Team who are determined to help us affect change – could your organisation be a part of this?

We pro-actively seek to engage with trusts who are sympathetic to the aims of our innovative and ground-breaking work. If you feel you can help us in any way, please contact Liz Gregg-Smith at lizgs@throatcancerfoundation.org
Thank you